"I am an idealist. I don't know where I'm going but I'm on my way."

Carl Sandburg

This ALERT functions as a vehicle of communication between the Alliance and its constituency. It is our goal to provide timely and useful material in a readable, easy access format. Feel free to send in your announcements, share your ideas or ask for help.

SCREENING FOR JOSEPH DISEASE • The International Joseph Diseases Foundation is organizing a screening clinic in Miami, Florida in September for persons afflicted or at risk or who suspect they may be affected with Joseph Disease (also known as Machado Disease on the east coast, especially in Massachusetts). There is no charge for the neurological examination and genetic counseling will be provided. Joseph Disease affects people of all nationalities and races. If interested, write to IJDF, P.O. Box 2550, Livermore, CA 94551-2550; TEL: 510/443-4600.

RAINBOW OF HOPE: A GUIDE FOR THE SPECIAL NEEDS CHILD • Written by Toby Levin, doubly qualified as a journalist and as the grandmother of a child with a rare genetic disorder, this book offers a sensitive, current and comprehensive presentation of both the emotional components of parenting a child with a birth defect and the scientific ramifications of the galloping pace of genetic discovery. Toby effectively allows parents to speak for themselves and provides a well researched resource list of services and treatments for families with children with birth defects. The Alliance commends the author for offering extended hope to our families with genetic concerns in her clearly written history of the Human Genome project and her account of the exciting advances in genetic counseling, testing and gene therapy. Special price for Alliance members: $9.95. Retail price: $12.95. Contact Starlight Publishing Company, 1893 NE 164 St., Suite 100, North Miami, FL 33162; TEL: 305/944-8446.

A HANIFUL OF HOPE: Helpful Suggestions for Grandparents of Children with Disabilities • Written by Mary J. Pinkava, this 9-page booklet helps grandparents grow in the understanding that their grandchild is just that — a child — and that his or her disability is only a part of the whole child. Written primarily for families who have recently received a diagnosis. Available for $2 from Pilot Parent Partnerships, 2150 E. Highland Ave., Suite 105, Phoenix, AZ 85016; TEL: 602/468-3001 or in Arizona: 800/237-3007. (From Lowe's Syndrome newsletter)

"YOU'RE IN THE PICTURE: How Citizens Affect Public Policy" • This 13-minute video from the National Health Council addresses four general areas for effective advocacy: Understanding the legislative process; Preparation; Communication; Follow-up. Available to members from the Alliance office on loan.

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